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Measurement and valuation of informal care: inclusion in economic evaluations

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Outcomes beyond the QALY



- Identification of effects in informal caregivers
- Measurement of effects > QALY

Informal care



Informal care is often preferred option

- Patients want in-home care
- Caregivers derive fulfillment

Impact of informal care is substantial

- >10% severe subjective burden*
- Variety of problems

*" I tried working full-time, I just couldn't do it. So I cut back my hours […]" ***

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* SCP 2009/2010

** SAWATZKY, J. E. and FOWLER-KERRY, S. (2003), Impact of caregiving: listening to the voice of informal caregivers. Journal of Psychiatric and Mental Health Nursing, 10: 277–286

Why should we include informal care in economic evaluations?



Role of informal care is substantial

- A patient is not isolated
- 1 in 5 in the Netherlands
- Important part of health care system

Inform policymakers

- Substitute for formal care, but not free of costs
- Level of burden
- Support programmes
- Cost-effectiveness respite care

Why should we include informal care in economic evaluations?



Health Care perspective

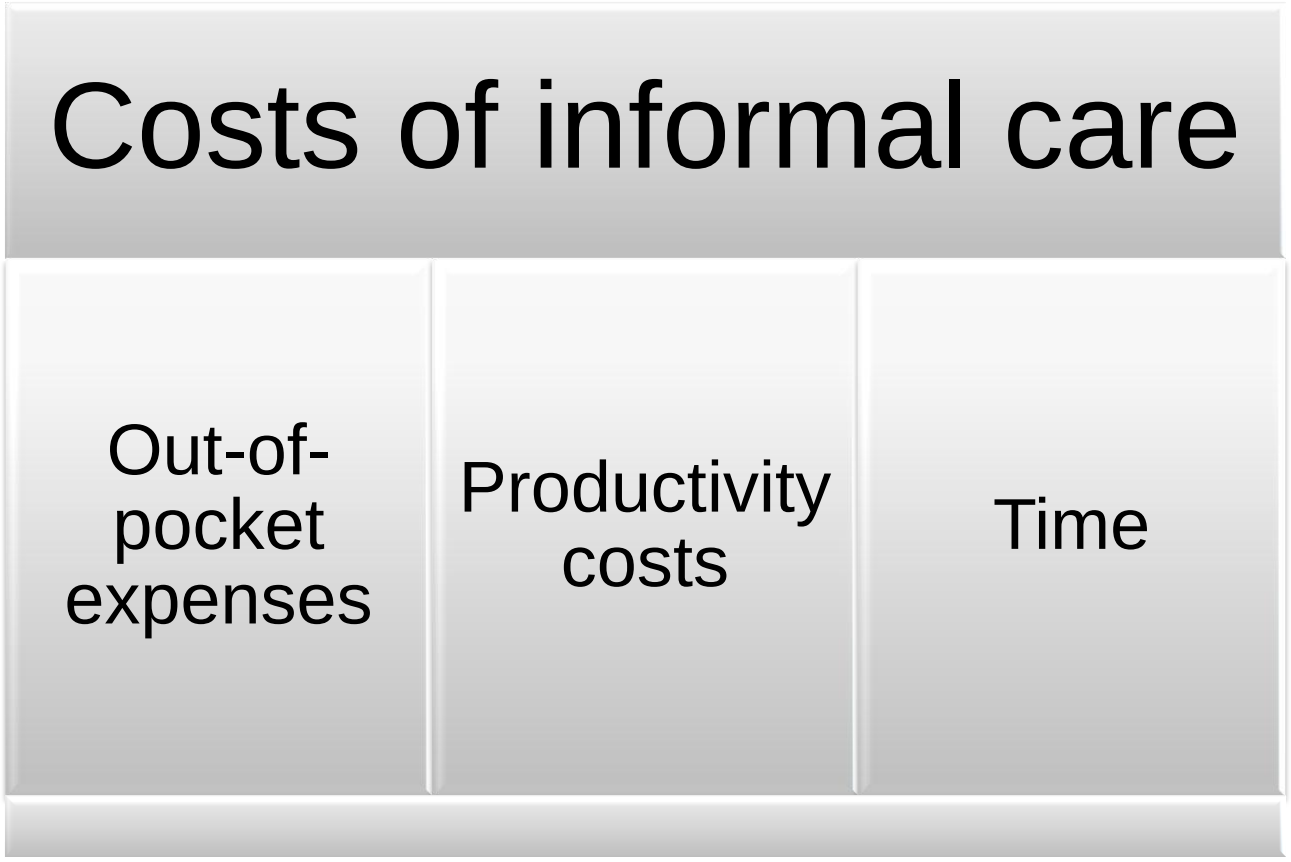
- Health care budget
- Δ Health care cost / Δ Health effects patients / **caregiver**

Societal perspective

- Broad societal perspective
- Δ Health care cost + Δ Other sectors + Δ Patient/**family** + / Δ Effects patients + Δ Other sectors + Δ **Family**

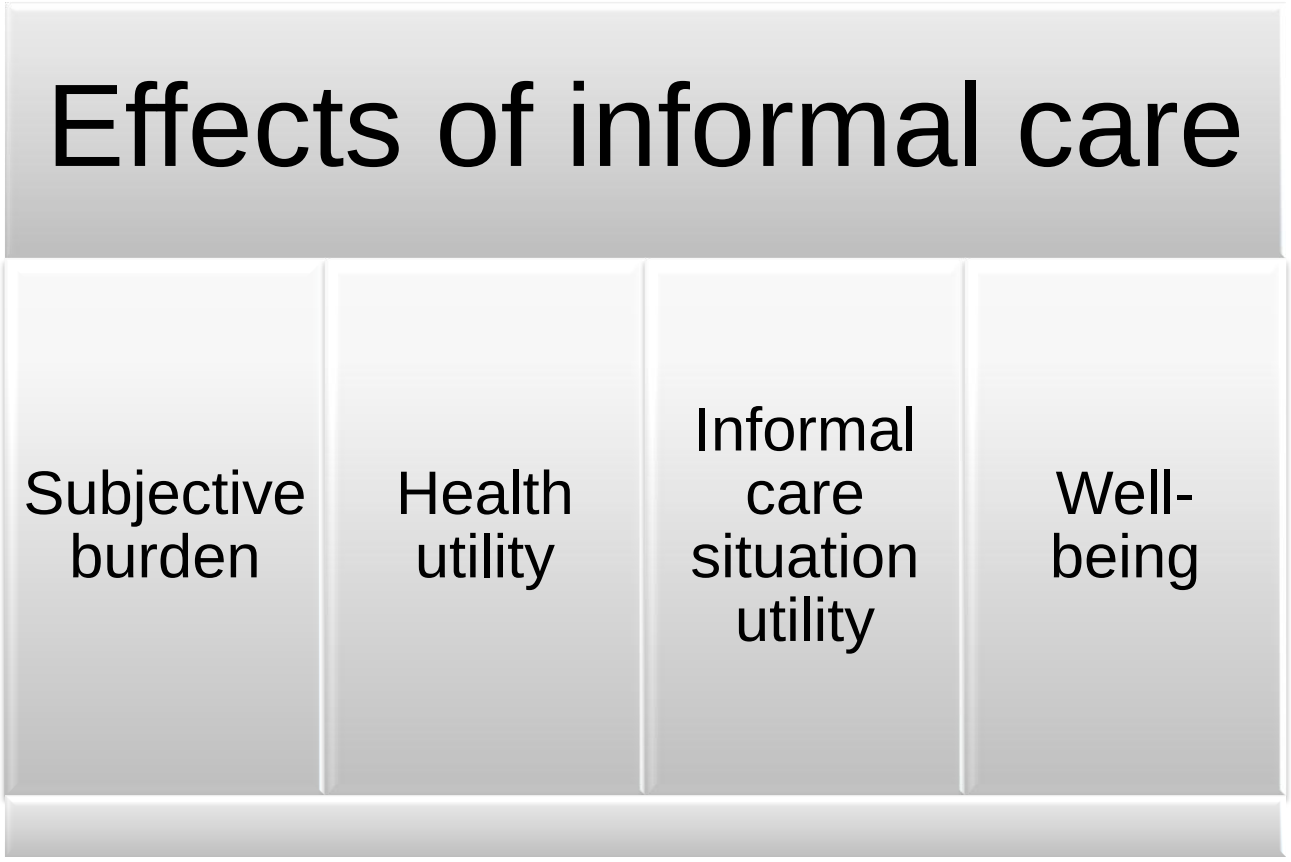
How can we measure impact of informal care?





How can we measure impact of informal care?





Effects of informal care



Subjective burden	• Overall strain of caring by caregiver • Caregiver Strain Index (CSI) • Self-rated burden scale (SRB)
Health utility	• Patient: EQ-5D, SF-36
Informal care situation utility	• Caregiver Experience Scale • CarerQol instrument
Well-being	• Happiness score

Effects of informal care



Subjective burden	• Rich description of impact • Measurement only, no preference information
Health utilities	• Compatible with health related QALY model • Health only
Informal care situation utility	• Full valuation of impact • Not compatible with health related QALY model
Well-being	• Effects > caregiving • Not compatible with health related QALY model

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Well-being	• Effects > caregiving • Not compatible with health related QALY model

CarerQol instrument



We would like to form an impression of your caregiving situation.
Please tick a box to indicate which description best fits your caregiving situation at the moment.

Please tick only one box per description: 'no', 'some' or 'a lot of'.

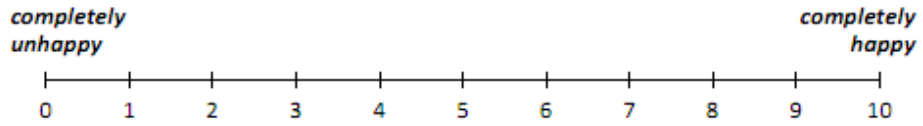
CarerQol-7D

	no	some	a lot of	
I have	☐	☐	☐	fulfilment from carrying out my care tasks.
I have	☐	☐	☐	relational problems with the care receiver *(e.g., he/she is very demanding or behaves differently; we have communication problems).*
I have	☐	☐	☐	problems with my own mental health *(e.g., stress, fear, gloominess, depression, concern about the future).*
I have	☐	☐	☐	problems combining my care tasks with my own daily activities *(e.g. household activities, work, study, family, leisure activities).*
I have	☐	☐	☐	financial problems because of my care tasks.
I have	☐	☐	☐	support with carrying out my care tasks, when I need it *(e.g., from family, friends, neighbours, acquaintances).*
I have	☐	☐	☐	problems with my own physical health *(e.g., more often sick, tiredness, physical stress*

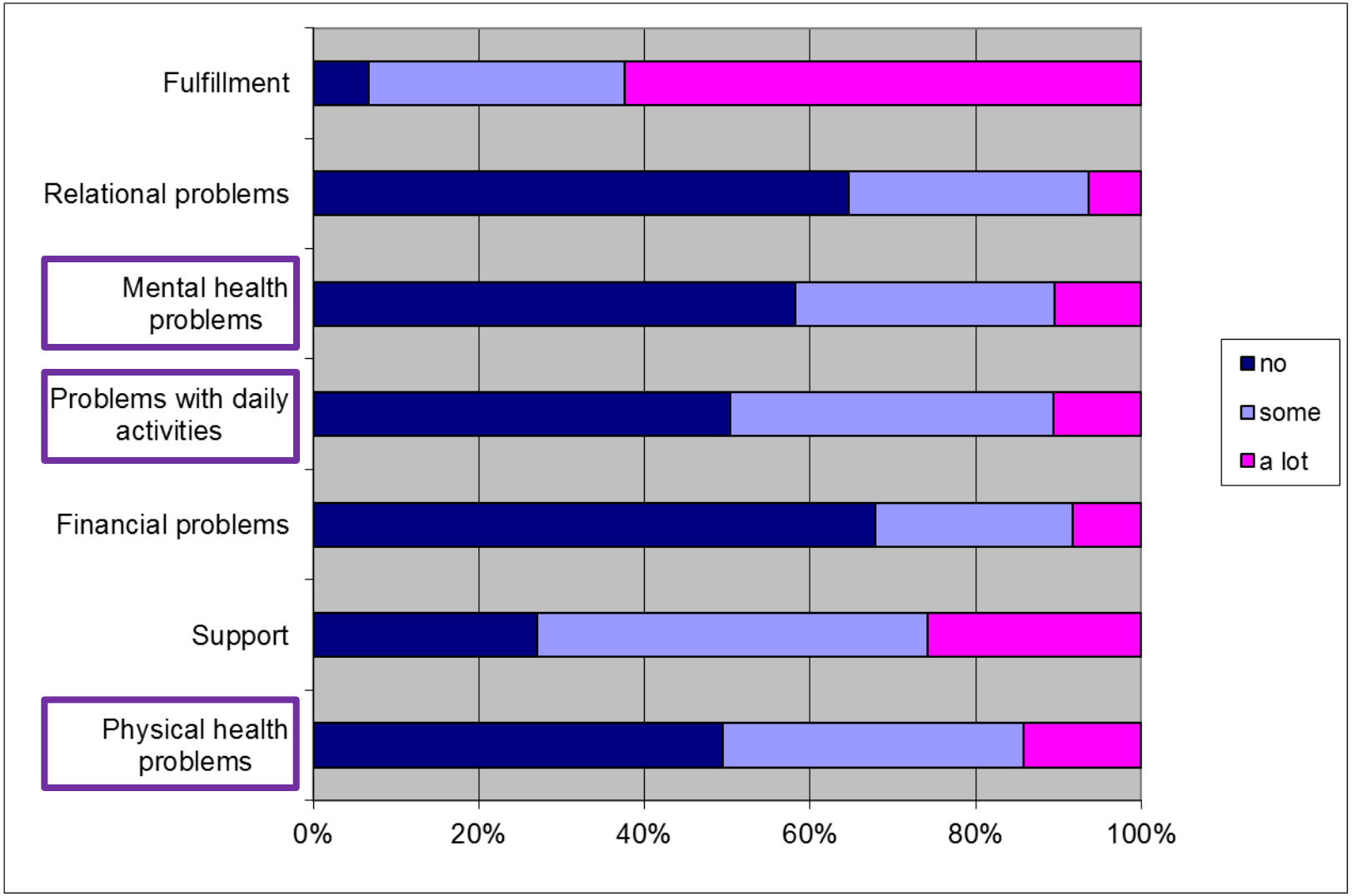
How happy do you feel at the moment?

CarerQol-VAS

Please place a mark on the scale below that indicates how happy you feel at the moment.



Burden of care giving



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Informal care situation related utility score



Subjective burden

- Two positive dimensions
- Five negative dimensions

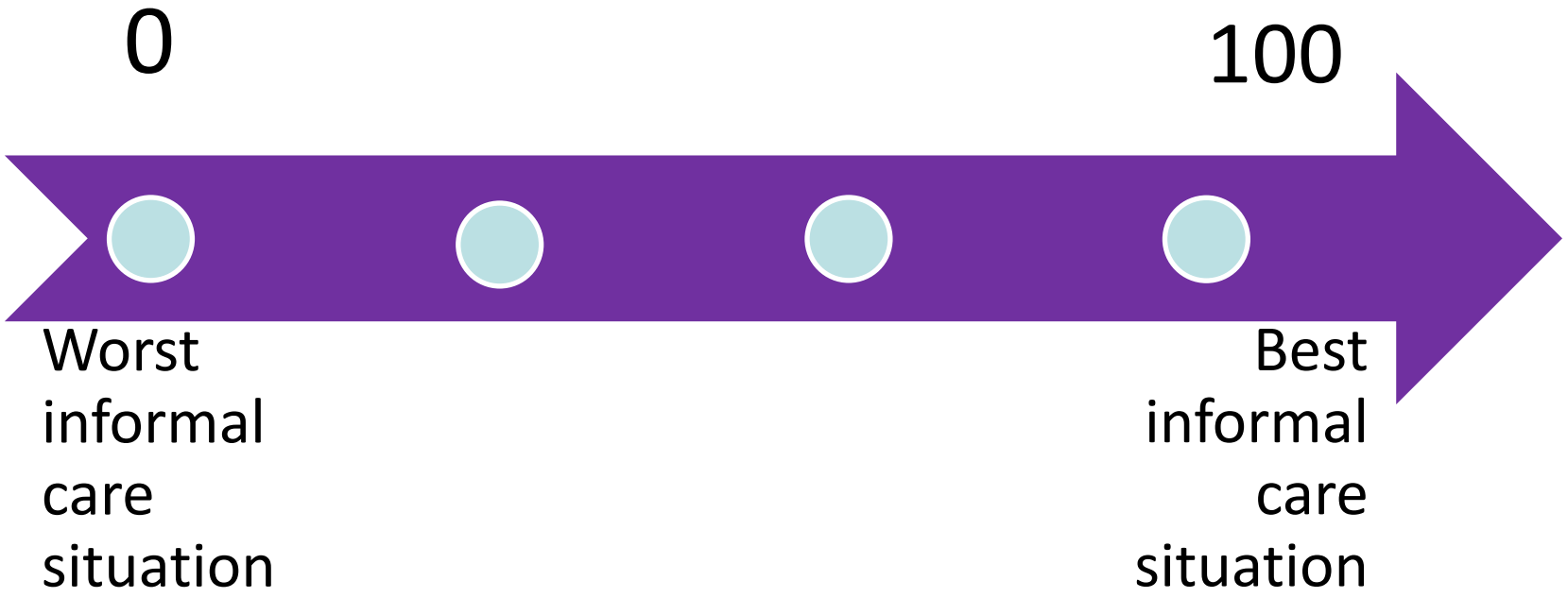
Sum score

- Some dimensions might be more severe than others
- Correct for severity of problem:
  - Weights per dimensions
  - Discrete choice experiment (DCE)
  - General public

Informal care situation related utility score



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CarerQol-7D tariff



Dimension	Tariff for score		
	no	some	a lot
Fulfilment	0.0	15.0	19.6
Relational problems	13.5	10.6	0.0
Mental health problems	13.5	10.4	0.0
Problems daily activities	10.2	6.1	0.0
Financial problems	15.1	11.7	0.0
Support	0.0	4.2	6.5
Physical health problems	15.0	15.6	0.0
plus: interaction-term	no	yes	
No mental health problems *and* no physical health problems	0.0	6.6	

CarerQol-7D tariff



Caregiver with some fulfilment, some relational problems, no mental health problems, a lot of daily activities problems, no financial problems, some support and no physical health problems…

Dimension	Tariff for score		
	no	some	a lot
Fulfilment	0.0	15.0	19.6
Relational problems	13.5	10.6	0.0
Mental health problems	13.5	10.4	0.0
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Financial problems	15.1	11.7	0.0
Support	0.0	4.2	6.5
Physical health problems	15.0	15.6	0.0
plus: interaction-term	no	yes	
No mental health problems *and* no physical health problems	0.0	6.6	

…Informal care situation utility score is 80.



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Informal care situation related utility

Caregiver:
Older age
Part-time paid work
Better health
Less depressive symptoms

Care recipient:
Female
Better mental health

Care situation:
Less hours p/week
Not sharing household with care recipient
Other informal caregivers
No formal care resources

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Use of informal care situation related utility score



Research on burden and support of caregivers & medical research:

- Subjective burden
- Weighted sum score taking into account differences in severity of problems

Use of informal care situation related utility score



Economic evaluations:

- Effect
- Informal care situation-related utility
  - Cost-utility analysis of respite care:
    - » main outcome
  - Cost-consequence / multi-criteria analysis:
    - » separate item

Informal care in economic evaluations



Intervention targeted at patients

MONETARY VALUATION INFORMAL CARE - PARTIAL VALUATION IMPACT INFORMAL CARE

		Type of economic evaluation				
Concept	**Valuation method**	**CMA**	**CBA**	**CEA**	**CUA**	**MCA**
Time input caregiver	OC, opportunity costs time	C	C	C (E:QALY)	C (E:QALY)	C (E:QALY)
	PG, opportunity costs time	C	C	C (E:QALY)	C (E:QALY)	C (E:QALY)
	CV1, value of time	C	C	C (E:QALY)	C (E:QALY)	C (E:QALY)
	CA1, value of time	C	C	C (E:QALY)	C (E:QALY)	C (E:QALY)
	CV2, value of time including influence of health cg	C	C (E:None)	C (E:None)	C (E:None)	C (E: None)
	CA2, value of time including influence of health cg	C	C (E:None)	C (E:None)	C (E:None)	C (E: None)

MONETARY VALUATION INFORMAL CARE - FULL VALUATION IMPACT INFORMAL CARE

		Type of economic evaluation				
Concept	**Valuation method**	**CMA**	**CBA**	**CEA**	**CUA**	**MCA**
Time input caregiver	CV3, value of time cg including influence of broader aspects	C	C (E:None)	C (E:None)	C (E:None)	C (E:None)
	CA3, value of time cg including influence of broader aspects	C	C (E:None)	C (E:None)	C (E:None)	C (E:None)
Well-being cg	Well-being method (WB)	C	C (E:None)	C (E:None)	C (E:None)	C (E:None)

NON-MONETARY VALUATION INFORMAL CARE -PARTIAL VALUATION IMPACT INFORMAL CARE

		Type of economic evaluation				
Concept	**Valuation method**	**CMA**	**CBA**	**CEA**	**CUA**	**MCA**
Health-related quality of life cg	Quality-Adjusted Life Year (QALY)	No	No	E (C: OC, PG, CV1, CA1)	E (C: OC, PG, CV1, CA1)	E (C: OC, PG, CV1, CA1)

NON-MONETARY VALUATION INFORMAL CARE -FULL VALUATION IMPACT INFORMAL CARE

		Type of economic evaluation				
Concept	**Valuation method**	**CMA**	**CBA**	**CEA**	**CUA**	**MCA**
Well-being cg	CarerQol-VAS (CQ-VAS)	No	No	No	No	E (C: None)
Informal care situation-related utility	CarerQol Tariff (CQ Tariff)	No	No	No	No	E (C: None)

OC=Opportunity cost method, PG=Proxy good method, CV=Contingent valuation method, CA=Conjoint analysis method
cg: informal caregiver
C: cost side, E: effect side, brackets: possible combination with other measure of informal care

iMTA Valuation of Informal Care Questionnaire (iVICQ)



http://bmg.eur.nl/imta/ivicq

